Factors correlated with disclosure of HIV infection in the French Antilles and French Guiana: results from the ANRS-EN13-VESPA-DFA Study.

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Acknowledgments

The ANRS-EN13-VESPA study was funded by the ANRS. We thank all patients who participated in the study, as well as the healthcare staff in Guadeloupe (G. Bombereau, F. Boulard, F. Cheret, E. Duvallon, MT. Georger-Sow, B. Giffo, S. Lapoussin, I. Lamaury, ML. Batard, A. Belleoud, P. Muller, K. Samar, V. Tarer), French Guiana (F. Alvarez, H. Claverie, P. Couppié, M. El Guedj, O. Magnien, S. Mason, V. Nasser, M. Renau-Ferrer, S. Robaday, T. Vaz), Martinique (S. Abel, V. Beaujolais, A. Cabié, D. Cales-Quist, V. Cornely, JF. Delord, S. De Thore, C. Opique) and Saint-Martin (F. Bissuel, V. Walter). Thanks also to Angela M.C. Rose (Epicentre, Paris) for helpful comments on the manuscript.

Abstract

OBJECTIVES: To determine the rate, patterns and predictors of HIV disclosure in a predominantly heterosexual population in the Caribbean region.

METHODS: A cross-sectional survey was carried out among a 15% random sample (n= 398) of the hospital caseload in all 9 hospitals providing HIV care in French Antilles and French Guiana. Information was obtained from a face-to-face questionnaire and from medical records. Determinants of disclosure to 1) steady partner and 2) other members of the social network were analysed using logistic regression.

RESULTS: From the time of diagnosis, 84.6% of those in a couple (n=173) disclosed their HIV+ status to their steady partner/spouse, 55.6% disclosed to other close relatives and friends and 30.3% did not tell their status to anyone. Disclosure within steady partnership was less likely among non-French individuals (Haitians: aOR 0.11 [95%CI 0.02-0.72], other nationalities: aOR 0.13 [0.02-0.68]), and among patients diagnosed since 1997 (aOR 0.21 [0.05-0.86]). Determinants of disclosure to the family, friend or religious network were found to be gender (women: aOR 2.04 [1.24-3.36]), age at diagnosis (>=50 years vs <30 years: aOR 0.42 [0.19-0.90]), nationality (Haitians vs French: aOR 0.39 [0.19-0.77]), transmission route (non-sexual vs sexual: aOR 3.38 [1.12-10.23]) and hospital inpatients (hospitalised vs non-hospitalised patients: aOR 1.98 [1.17-3.37]). A marginally significant association was found between eduction and disclosure: less educated people disclosed less often both to steady partner and to their social network. After disclosing, most persons living with HIV/AIDS received social and emotional support from their confidants. Discriminatory attitudes were infrequent.

CONCLUSIONS: In this study, almost one third of persons living with HIV/AIDS had not told anyone that they were HIV positive. Interventions targeting the general population and social institutions, and support of PLWHA by healthcare staff are needed to improve the situation.

Disclosure of HIV status to significant others, either lovers, family or friends, has been shown to be a potent stressor, as individuals living with HIV/AIDS might fear negative reactions such as blame, rejection or violence [1,2,3]. However, the HIV person's balance of potential risks and benefits of secrecy versus disclosure has been shown to be fundamental in coping with an HIV diagnosis and for accessing emotional and social support. Disclosure might also be considered to be an expression of responsibility towards a spouse or sex partners [1]. Disclosure is a planned and selective behaviour which responds to the HIV+ person's balance of potential risks and benefits of secrecy and disclosure.

Progression of HIV might precipitate disclosure due to visible signs of disease or an urgent need for emotional support [4]. However, as HAART has caused HIV infection to become a chronic condition, this situation might have become less frequent, at least in countries with accessible treatment. Among the various determinants of disclosure behaviour, cultural factors have been identified, both regarding level and pattern of disclosure. People with Latino ethnicity in the USA, either homo/bisexual males or heterosexual sub-groups, appear less likely to disclose their status to their circle of family or friends than Whites or African-Americans [5,6]. Friends appear to be closer confidants than immediate families among gay men, while relatives might be chosen as confidants over spouses among HIV+ African women [7].

Various assumptions have been made regarding the origins of such situations in social norms, related to sexuality, gender and family roles. Fear of being a burden to the immediate family, or stigma associated with HIV infection, might force persons living with HIV/AIDS (PLWHA) to keep their disease secret from their social network, as has been shown in Asian populations [8,9].

Time since diagnosis, health status and disease progression [4,10], age (both of the HIV-infected person and of the potential confidant [11]), education [12], and gender have been found to correlate with disclosure [2,13], but results are inconsistent across studies depending on the period, the population and the study design.

Located in the second most affected region in the world [14], the French overseas territories of Guadeloupe, Martinique, French Guiana and St Martin (with a total population of one

million) share the Caribbean features regarding HIV epidemics driven mostly by heterosexual transmission [15]. The 2003 ANRS-EN13-VESPA study provided the opportunity to assess disclosure patterns in Caribbean culture among mostly heterosexual subgroups of PLWHA, by gender, cultural and social factors, and disease progression.

Materials and methods

Subjects and design

A cross-sectional survey was carried out in all 9 hospital settings caring for HIV+ patients in Martinique, Guadeloupe, the French half of the island of St Martin, and French Guiana, from September 2003 to January 2004. Fifteen percent of each hospital's total caseload was sampled (from a total estimated number of 2700 HIV+ patients for the four territories). Eligibility criteria were: being 18 or older, being infected with HIV-1, being diagnosed for 6 months or longer, and non-French individuals being followed up for 6 months or more. Patients with severe physical or mental impairment (as assessed by their attending physician) were not asked to participate. Subjects were randomly selected during their regularly scheduled appointment. Among 1339 eligible patients, 694 were randomly selected of whom 51 were excluded because of severe impairment and 239 declined participation; a total of 404 persons (62.8%) were enrolled. Questionnaire administration took place at the hospital clinics. Respondents received a 15 euro voucher. After excluding six participants because of incomplete data, 398 individuals were included in the statistical analysis.

Persons were administered a questionnaire either in French, Creole or other languages (Bushinenge languages in French Guiana, English in St Martin) by trained interviewers. Medical information was documented from the patient's medical record. The questionnaire covered a range of social issues (history of testing and treatment, employment, income and living conditions, parenthood, sexuality, social network and disclosure).

Methods

Self-disclosure was defined as the patient him/herself telling his/her HIV status to steady partner/spouse, mother, father, brothers/sisters, extended family, friends, priests and folk

healers, at any time since diagnosis. Second-hand disclosure was defined as an indirect disclosure (ie HIV status disclosed but not by the patient him/herself) and was documented for each type of network member. Information was asked about social support and discrimination (rejection, disrespect, discrimination because of HIV serostatus) from each category of confidants, as possible consequences of disclosure.

For each member of the social network, rates of self and second-hand disclosure were calculated after exclusion of inapplicable responses. Two indicators of disclosure were computed: one to account for disclosure to any close relatives, friends or religious personnel; the other for disclosure to a steady partner. The determinants of these two variables were also investigated. Correlates considered in statistical analysis were 1) the territory (St Martin**,** Guadeloupe, Martinique and French Guiana), since despite common cultural features these are heterogeneous regarding history, ethnicity and economic situation; 2) gender; 3) age at diagnosis (<30, 30-39, 40-49, >=50 years); 4) ethnicity, explored on the basis of nationality (French, Haitian, other) since ethnic group membership is not documented in France; 5) education, divided into three categories: no or primary school, secondary school, high school or higher; 6) employment either in the formal or the informal market (yes, no); 7) time since diagnosis (<=1996, >1996); 8) hospitalisation since diagnosis and presence of AIDS, since these have been found to be predictors of disclosure in various studies; 9) route of transmission (male-to-male sex, heterosexual sex, other: including injecting drug use, blood transfusion, and unknown).

Descriptive results were tabulated after weighting within each hospital by the reverse of the frequency of consultation to take into account sampling bias (patients who attend outpatient clinics more often being more likely to be selected than those who attend infrequently).

Predictors of disclosure to a steady partner and disclosure to the social network were evaluated by using the Pearson χ^2 test and multiple logistic regression modelling, taking into account the hospital stratification within the survey design, using Stata for Windows version 9.1 (StataCorp, College Station, Texas, USA).

Results

The main characteristics of the study participants are described in table 1.

At the time of data collection, overall 69.7% of respondents had disclosed to at least one person and 30.3% of them had not told anyone they were HIV positive. Among 173 participants, 44.2% had a steady partner/spouse, to whom the majority (84.6%) had disclosed their HIV status (Table 2). Non-French citizens disclosed their HIV status less frequently to their steady partner than French citizens. A shorter time since diagnosis was associated with a lower rate of disclosure while other variables (transmission group, stage C, hospitalisation since diagnosis) were not associated with disclosure. Both nationality and time since diagnosis remained associated with disclosure in logistic regression: patients diagnosed since 1997 were less likely to disclose their HIV infection to their partner or spouse (aOR 0.21 [0.05-0.86]), Haitians less likely than French nationals (aOR 0.11 [0.02-0.72]), and respondents with secondary education less likely than those with high school or university degrees (aOR 0.28 [0.08-1.01]). However, the latter association did not reach statistical significance (p=0.052)

Most people had a large social network with at least six persons or categories of possible confidants for 75.0% of the respondents. Rates of disclosure among immediate or extended family or friends were much lower than within a couple: 32.4% disclosed to mothers, 32.2% to siblings, 26.2% to friends, 22.3% to fathers, 20.5% to children, and 19.6% to other relatives. While most respondents reported strong religious feelings, few told their HIV diagnosis to priests or traditional healers (10.9% and 3.3% respectively).

The prevalence of disclosure to anyone in the social network (not taking into account disclosure to spouse/steady partner) was 55.6%. Disclosure to relatives or friends did not depend on whether persons had a steady partner or not, although individuals who had a steady partner and concealed their status to him/her were less likely to disclose it to their social network (36.7% vs. 61.3%, p=0.02).

Rates of disclosure were higher among respondents from St Martin. Only 38.1% of Haitians had disclosed their status compared with over 60% of French or other respondents. Disclosure decreased with increasing age at diagnosis, and by level of education. The small subgroup of persons with a non-sexual transmission route (n=22) were more likely to have disclosed their HIV status to their network. No association was found between disclosure and either stage of disease or time since diagnosis.

In multivariate logistic modelling, male gender, age over 50 years at diagnosis, Haitian nationality, and sexual transmission of the virus were associated with lower disclosure within the social network. Moreover, hospitalisation since diagnosis increased the likelihood of disclosure.

Among persons aware of the patient's HIV infection, supportive attitudes were frequent: persons reported a high level of support, ranging from 64.6% (from fathers) to 75.7% (from children). Only religious personnel were reported as less supportive (34.0%) (data not shown, full data available from the authors on request). Prevalence of discrimination after direct or indirect disclosure was 6.6% in the family circle and 10.5% from friends.

Second-hand disclosure was low, ranging from 1.6% among children to 5.0% in the extended family. Finally, 11.7% of those who disclosed to their spouse and 16.8% of those who disclosed to other persons in their social network had experienced a breach of confidentiality.

Discussion

In the French Caribbean and Guyanese regions, most people living with HIV/AIDS had disclosed their HIV seropositivity to their steady sex partner/spouse while just over half had disclosed their HIV status to someone in their social and family network, with little difference between immediate or extended family or friends. Priests or traditional healers were infrequently used as confidants. Nearly one-third of respondents however had not told anyone about their HIV status. Indirect disclosure was rare. The low rate of disclosure might have been underestimated by participation bias since persons more likely to be secretive might have been more likely to decline participation.

For couples, spouse/steady partner appears to be the first and the most reliable confidant, and disclosing their HIV status seems to make it easier to tell other friends and family members. This finding differs from observations among pregnant Tanzanian HIV+ women who were more likely to tell their status to a female relative when it was concealed from their spouse [7]. Compared with available data among heterosexual populations, rates of disclosure in the other segments of the social network are much lower in our sample [2,13,16]. For example, O'Brien [13] assessed disclosure in a mixed population in New Orleans, Louisiana, 69.8% to

an immediate family member within a median of 2.7 years from diagnosis. However, the low rates observed in our mostly Creole sample is consistent with lower rates of disclosure among Latino populations compared with Whites and African-Americans in the USA [5,6]. In our sample, compared with French citizens, non-French citizens, especially Haitians were less likely to tell their HIV status. This might be because they could be exposed to a double discrimination, first as Haitians, second as PLWHA: discrimination and racism against Haitians - who are the larger migrant population in these regions - is common among the local population; moreover HIV-related stigma was shown to be common both in Haiti [17,18] and in immigrant Haitian communities in North America [19,20].

As most individuals are middle aged, more than a quarter being diagnosed with HIV in late adulthood, age might also explain infrequent disclosure to parents, as shown by Serovich among gay men [11]. Moreover, more than half of the patients were diagnosed in the HAART era, which has turned HIV infection in a chronic condition and might lessen the need for support [11].

Within couples, no difference was found between males and females. Regarding family and friends, males appeared more reluctant to disclose their HIV infection. In studies considering both men and women, inconsistent results have been found regarding gender [2,13]. In the local Creole culture, homophobia has decreased but is still common [21,22]; thus HIV+ heterosexual men might fear being viewed as having had sex with males. The marginally significant association observed in our population between education and disclosure is consistent with decreased tolerance towards PLWHA observed among the less educated in the general population [22]. Among PLWHA in Burkina Faso, illiterate women disclosed less their status to their steady partner than the more educated ones [12].

Disclosure appears to be a very selective behaviour, since few members in the social network are told about an HIV diagnosis, and in turn most confidants keep the information secret from other members in the family circle [20]. However, emotional and/or material support to the HIV infected person are the most common attitudes after disclosure, in line with the Serovich theory of competing consequences [4]. The increased risk of disclosure among people with an inpatient hospital stay might reflect both the difficulty of avoiding disclosure when the disease has become “visible” and the need for social support when adverse health events occur. These

attitudes regarding disclosure might be viewed as effects of stigmatisation demonstrated in the KABP survey carried out in the region in 2004 [22].

In societies where religion is a major social institution along with traditional healers, religion is expected to provide support to suffering people. Actually in these regions, most Christian Churches are expressing conservative morals on sex, gender roles and HIV/AIDS, preventing affected individuals from seeking support from religious personnel, as observed in the present study. However responses regarding disclosure to traditional healers might have been underestimated, since patients could have concealed such lay practices in interviews which took place at the hospital outpatient clinic.

In a society with poor tolerance towards PLWHA, anticipation of negative reactions and internalisation of stigma act as barriers to disclosure and further, to effective emotional and social support. These phenomena might prevent HIV infected persons from revealing their infection and persons at risk from seeking voluntary counselling and testing [3,7]. Late diagnosis has also been observed in these French regions [23,24] where testing and treatment are available. Both phenomena, late diagnosis and difficulties in disclosure, might be viewed as consequences of the poor tolerance towards people with HIV in these regions as shown in the 2004 general population survey. Thus, support to persons living with HIV in hospital settings and through self-help groups should be improved along with programmes targeting the general population and institutions such as the media, churches and political leaders.

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Table 1. Description of the study sample. n=398 ANRS-EN13-VESPA Study

	n (%[a])
Territory	
Saint-Martin	30 (7.7)
Guadeloupe	138 (34.8)
Martinique	91 (22.7)
French Guiana	139 (34.8)
Gender	
Male	209 (52.5)
Female	189 (47.5)
Age	
<=30	38 (9.6)
30-49	246 (62.4)
>=50	114 (28.0)
Nationality	
French	227 (59.0)
Haitian	114 (27.5)
Other	57 (13.5)
Education	
None or primary school	157 (37.9)
Secondary school	161 (39.8)
High school or more	80 (22.3)
Employment	134 (38.4)
Steady partnership	173 (43.20)
Date of HIV diagnosis	
<= 1996	180 (44.6)
>1996	218 (55.4)
Mode of HIV acquisition	
MSM	52 (13.7)
Heterosexual	324 (80.9)
Other	22 (5.4)
CDC Stage C	112 (25.4)
Hospitalisation since diagnosis	104 (22.4)
Current ARV treatment	305 (74.3)

[a] weighted %.

Table 2. Factors associated with disclosure to steady partner/ spouse and disclosure to at least one confidant in the social network (immediate and extended family, friends, priests, folk healer) : univariate and multivariate analyses. ANRS-EN13-VESPA Study

	Steady partner/spouse			Social network		
	Univariate		Multivariate	Univariate		Multivariate
	n[a] (%[b]) disclosed	p-value	OR (95% CI)	n[a] (%[b]) disclosed	p-value	OR (95% CI)
	173 (84.6)			**398 (55.6)**		
Territory						
St Martin	13 (87.1)		2.20 (0.12-39.60)	30 (66.7)		2.69 (1.02-7.05)*
Guadeloupe	49 (85.1)		1	138 (56.6)		1
Martinique	46 (91.6)		1.46 (0.38-5.56)	91 (63.2)		0.96 (0.53-1.75)
French Guiana	65 (78.8)	0.35	2.09 (0.45-9.62)	139 (47.1)	0.08	0.83 (0.45-1.51)
Gender						
Male	88 (86.7)		1	209 (52.3)		1
Female	85 (82.5)	0.43	0.59 (0.22-1.60)	189 (59.1)	0.18	2.04 (1.24-3.36)**
Age at diagnosis						
<30	61 (88.9)		1	108 (65.8)		1
30-39	59 (85.1)		0.49 (0.16-1.52)	133 (57.2)		0.77 (0.43-1 .38)
40-49	33 (82.8)		0.75 (0.22-2.63)	92 (54.3)		1.11 (0.57-2.14)
>=50	20 (73.1)	0.39	0.23 (0.04-1.27)†	65 (36.4)	0.003	0.42 (0.19-0.90)*
Nationality						
French	102 (92.4)		1	227 (62.3)		1
Haitian	44 (71.5)		0.11 (0.02-0.72)*	114 (38.1)		0.39 (0.19-0.77)**
Other	27 (70.2)	0.001	0.13 (0.02-0.68)*	57 (61.6)	0.15	0.92 (0.44-1.93)
Education						
None or primary school	52 (77.5)		0.59 (0.12-3.04)	157 (40.3)		0.49 (0.24-1.01)†
Secondary school	82 (84.2)		0.28 (0.08-1.01)†	161 (62.9)		0.90 (0.49-1.66)
High school or more	39 (93.0)	0.21	1	80 (68.3)	<0.001	1
Date of HIV diagnosis						
<= 1996	76 (95.1)		1	180 (59.6)		1
>1996	97 (76.4)	0.002	0.21 (0.05-0.86)*	218 (52.3)	0.15	1.03 (0.63-1.69)
Mode of HIV acquisition						
Male-to-male	20 (90.1)			52 (63.9)		1.49 (0 .73-3.03)
Heterosexual	144 (82.9)			324 (52.5)		1
Other	9 (100)	0.39		22 (80.1)	0.03	3.38 (1.12-10.23)*
CDC Stage C						
No	130 (83.7)		1	286 (53.6)		1
Yes	43 (88.1)	0.12	1.00 (0.35-2.89)	112 (61.3)	0.16	1.45 (0.86-2.45)
Hospitalisation since diagnosis						
No	40 (91.5)		2.03 (0.54-7.69)	105 (65.9)		1
Yes	133 (82.9)	0.45	1	293 (52.5)	0.02	1.98 (1.17-3.37)*

[a] Observed number [b] weighted %

** p<0.01 * p<0.05 † p≤0.10